UMRI Data Requests Standard Operating Procedure

1.0   Aim

1.1   The aim of this standard operating procedure (SOP) is to outline the steps that would be taken by the principal investigator of the study in the event that a research volunteer requests their own Magnetic Resonance Imaging (MRI) data.

2.0   Background

2.1   Under the General Data Protection Regulation (GDPR – EU Regulation 2016/679) and the Malta Data Protection Act (Cap. 586 of the Laws of Malta - 2018), research volunteers have the right to request a copy of their personal data.

2.2   UMRI in agreement with the Data Protection Officer of the University of Malta aims to allow research volunteers to exercise this right as specified in the University of Malta Magnetic Resonance Imaging (UMRI) data management plan which may be found on the UMRI website.

2.3   As specified in the data management plan, research volunteers who participated in a study are able to request for a copy of their personal data including their own MRI scans upon a formal request to UMRI. Research volunteers may request for a copy of their personal data by filling the online form found on the UMRI website here.

3.0   Procedure

3.1   In the event that research volunteers contact UMRI for a copy of their data, UMRI will forward the form and/or the email received to the principal investigator of the study who will be informed that a research volunteer has requested data.

3.2   UMRI will ask the principal investigator to forward the patientID of the volunteer to the Scientific Officer or Shadowing Officer of UMRI (or a designated UMRI person). This is necessary as the link between the name of the volunteer and their MRI data may only be made through the patientID.

3.3   Before being sent to the volunteer, the data is to be put in one folder, compressed to a *.zip* file and encrypted.

3.4   The UMRI Scientific Officer should forward the data to the volunteer in a manner that is preferable to the volunteer. Ideally, data transfer is done through an encrypted external hard

drive, a USB stick or through an encrypted folder through a shared google drive folder. The usage of third party applications to transfer data should be avoided when possible.

3.5   If the data is shared via a shared google drive folder, the UMRI Scientific Officer or Shadowing Officer should send the link to the drive and the encryption key of the folder to the research volunteer by a **confidential email**.

3.6   The google drive folder is to be deleted after the volunteer confirms that the data has been downloaded.

3.7   UMRI (gdpr-UMRI.platform@um.edu.mt) should be kept in-copy during the process for record keeping purposes.

3.8   After a successful data transfer, the UMRI Scientific officer shall update the text file located in the UMRI repository which contains a list of the PatientID's that requested data.